

An Invitation

Dear Colleague,

On behalf of the International Society for Quality of Life Research (ISOQOL), it is our pleasure to invite you to the 7th Annual Conference that will be held in Vancouver, Canada 29-31 October 2000.

As we have worked on the program there seems to be an emerging theme concerning the "Interpretation of HRQOL measures" and the "Determination/measurement of a meaningful change in HRQOL." We hope that the special invited presentations from experts in the field, which are already part of the program, will initiate that discussion. But the success of the meeting will depend on the contribution of papers reflecting the state of the art of HRQOL research from multiple disciplines. Please send us abstracts of your best recent work and plan ahead for your participation in Vancouver. We hope that you will find the program prepared by the Scientific Program Committee interesting and challenging.

We would like to bring to your attention two new experimental presentation formats for this year. The first is a *Special Contributed Oral Session*. This format will allow members to organize sessions that they believe are important and timely. We will also have one fewer presentation during each Special Contributed Oral Session to allow for more extensive discussion of the topic. If you have an area that you think will be of special interest, please consider organizing one of these sessions. The second is the addition of parallel *Poster Discussion Sessions* that will allow for more interactive discussion of selected posters.

Vancouver is a very special place. We strongly recommend that you take the opportunity of both a productive professional meeting and an enriching personal experience.

See you in October in Vancouver.

Drs. Diane Fairclough, Carol Moinpour and David Osoba
Co-Chairs, 7th Annual Conference of ISOQOL

Provisional Program

Sunday, October 29

Workshops I
*Lunch
Workshops II
Welcome Reception

Monday, October 30

Breakfast Meetings
Welcome Address
Plenary Session
Oral Sessions I
Lunch with
Business Meeting
Masters Lectures
Posters-Meet the Author
Posters-Discussion Sessions
Oral Sessions II
Conference Dinner

Tuesday, October 31

Breakfast Meetings
Oral Sessions III
Oral Sessions IV
Lunch with Meet the Developer
Sessions
Special Contributed Papers
Posters-Meet the Authors
Posters-Discussion Sessions
Closing Session

The Plenary and Closing Session speakers and tentative titles:

I. Plenary

George Torrance: "Utility measurement of health-related quality of life: past, present, and future" (Discussant: **Les Lenert**)

Ron Hays: "When does a profile beat a single number, or are two always better than one?" (Discussant: **Dennis Revicki**)

II. Closing

Ian Tannock: "Health-Related Quality of Life: Where are we and where should we be going?"

*A formal discussion: People will be presenting pro's and con's to the topic: "Should Health-related quality of life assessments be incorporated into all clinical trials? Ethical and practical considerations." Facilitator: **Ivan Barofsky**. This lunch is not included in the registration fee. An additional fee of \$15 is required if you wish to receive lunch. Advance registration is necessary. Please see registration form.

English is the official language of the conference, no simultaneous translation.

Guidelines for Submission of Abstracts

You are invited to submit an abstract to the International Society for Quality of Life Research for presentation at our 7th Annual Scientific Meeting, October 29-31, 2000 in Vancouver, Canada.

Deadline: The abstract deadline for RECEIPT of your abstract is **May 31, 2000** (Special Contributed Sessions and/or Oral/Poster Sessions).

You may submit your abstract in one of two ways:

1. **On-line-** You will need a Web browser (Netscape Navigator, Microsoft Internet Explorer, Opera, etc.). Complete the abstract on-line. You will be asked to provide a password and you can work on the abstract over days or weeks. When you have completed your abstract, you “submit.” Once you submit, you will receive an e-mail message confirming successful receipt of the abstract; this e-mail message will also contain a copy of the abstract as received.

The website is available 24 hours a day until **11:59pm EST on May 31, 2000** from any location that has access to the internet.

Due to technical limitations of the World Wide Web, if your abstract contains any special characters not found on a standard keyboard, we recommend using the Traditional Paper Method to submit your abstract.

2. **The Traditional Paper Method-** You may submit abstracts in the more traditional method on paper if you are unable to do so on-line. **You will need to request a submission packet from the ISOQOL Executive Office.** You may do this in one of three ways:

- Call the ISOQOL Administrative Office (703-556-9222)
- Send a Postcard/Letter to:
ISOQOL
6728 Old McLean Village Drive
McLean, VA 22101-3906 USA
- Via Email (info@isoqol.org)

Acceptance: Notification will be sent by July 14, 2000. Authors whose abstracts are accepted are required to register by August 18.

Special Contributed Sessions

ISOQOL is going to experiment with a new scientific session format this year. The concept is to allow ISOQOL members to propose and organize a special contributed oral session consisting of 3-4 contributed oral papers with an optional discussant on a selected topic. One of the motivations for this format is to allow ISOQOL members to identify topics and speakers that are timely and of particular interest to the membership. The second motivation is to allow slightly more time for presentation or discussion than will be available in the regular oral sessions. The Scientific Program Committee will review both the concept and the individual abstracts. Based on that review, they will select the best combinations for presentation in this special format. Abstracts not selected for presentation in this special format will be automatically considered for oral or poster presentation unless otherwise requested. The organizer is responsible for providing 1) a title for the session, 2) a brief description of the session, 3) identification of abstract titles and speakers and 4) the identification of the discussant. The potential speakers are responsible for submitting an abstract in the standard format. **Deadline for all abstract submissions is May 31, 2000.**

Important Dates

May 31, 2000 ~ Abstracts due

July 14, 2000 ~ Notifications sent about acceptance

August 18, 2000 ~ Early registration deadline

Abstract Submission & Registration Info On-line
www.isoqol.org

Topics for Abstract Submission

Methodological and Theoretical Topics in QOL

1. Analytic Issues (longitudinal studies/missing data/multiplicity of endpoints)
2. Individualized Measures
3. Instrument Calibration/Equivalency among Scales
4. Interpretation of HRQOL data
5. Item Response Theory (IRT)
6. Modes of Administration
7. Proxy Measures
8. Psychometric Methods/Scaling
9. Qualitative Methods
10. Response Shift
11. Responsiveness/Interpretation
12. Scale Development/Validation
13. Scale Translation/Cultural Adaptation
14. Theories of Quality of Life
15. Utilities

Disease-Specific Applications of QOL Research

- A. Cardiovascular Disease
- B. Chronic Disease
- C. Dermatology
- D. Gastrointestinal Disease
- E. Gynecology/Obstetrics/Endocrine
- F. Infectious Disease/HIV/AIDS
- G. Musculoskeletal/Rheumatology
- H. Neurology
- I. Oncology
- J. Psychiatric Disorders/Substance Abuse
- K. Psychoneuroimmunology
- L. Respiratory Disease
- M. Surgery/Transplantation
- N. Urology/Nephrology

QOL in Special Populations

- O. Children
- P. Disability/Injury/Rehabilitation
- Q. Elderly
- R. End of Life care
- S. Family/Caregivers
- T. Minority Populations

QOL in Specific Research Settings

- U. Clinical Trials
- V. Disease Prevention/Public Health
- W. Epidemiology/Population based studies
- X. Health Services Research/Technology Assessment
- Y. Medical Practice/Quality of Care

Scientific Awards

ISOQOL presents five Annual Awards honoring individuals in three different categories.

ISOQOL is committed to promoting excellence in quality of life research. Therefore, again this year, the Young Investigator's Award will be presented during the conference closing plenary ceremony. This award recognizes the best overall oral presentation made by an individual under age 35.

In recognition of the vital role that posters play in communicating QOL research methods and findings, the Scientific Program Committee will also present three Best Poster Awards during the closing ceremony. A special jury organized by the Scientific Committee will judge all the posters.

Starting in 2000, an award will be given annually to someone who has advanced QOL research and has made outstanding contributions to ISOQOL. (More details to follow).

Training Workshops

Duration

All workshops will last 3 hours and will be held on Sunday, October 29 at the official Conference hotel.

Number of Participants

Individuals are encouraged to register as soon as possible--space is limited. A minimum number of participants will be required to organize a workshop.

Final Workshop Program

Workshop descriptions may be found on next page. For more information on those that have an incomplete listing in this brochure, please be sure to visit the ISOQOL website. Updates will be posted when information becomes available.

Workshop Registration Fee

The fee for workshop registration is US\$100 per workshop or US\$175 if you attend two workshops. After August 18, 2000 registration fee will be \$125 per workshop; or \$200 for two.

Workshop Topics and Speakers

Morning Session (9am-12pm)

1. Quality of Life Assessment: Introduction and Overview; *Sharon Wood-Dauphinée*

In this introductory workshop the following topics will be presented: conceptualization of the quality of life (QoL) construct; why and when should QoL be assessed; classification of QoL measures; modes of administration; selecting QoL measures; and issues related to analysis and interpretation. A generic and a disease-specific measure will also be completed by attendees on behalf of a simulated case history.

2. Assessing Clinical Significance for QOL Measurement; *Jeff Sloan/Tara Symonds*

The content of this workshop include a summary of the literature and approaches for assessing QOL. Examples drawn from clinical oncology trials will be involved. Hands-on experience at designing and analyzing QOL endpoints will be provided.

3. Individual Differences in QOL Treatment Responses; *Gary Donaldson*

In standard evaluation of quality of life outcomes in clinical trials, individual differences compose the error term for testing the hypothesis of mean population equality. An alternative approach recognizes that individual differences have systematic as well as error components. The systematic variation in individual responses provides directly relevant clinical information and also provides a context for interpreting the size of the mean treatment difference. Mixed model analyses provide a formal approach to the study of individual differences by including (random) person effects in the same model as (fixed) treatment effects. This session will demonstrate statistical and graphical description of individual differences, and explain how to represent and interpret their effects in mixed effects models.

4. Technical Aspects of Questionnaire Development; *Hanne Thorsen*

In recent years there have been major advances in methods for gathering questionnaire content designed to assess some form of subjective health status, for example, the use of face-to-face interviews with representatives of patient groups and focus groups. However, there has been a decline in the amount of attention paid to the more detailed aspects of questionnaire design such as the instructions to respondents, the format, layout and wording of items and interpretation of items by different groups. Also the choice of 'user friendly' response options seems to be a topic which is seldom discussed. All of these can have profound effects on

responses and missing data. The emphasis of the work shop will be on ensuring 'respondent friendliness' of questionnaires. The participants will be asked to complete several pre-existing questionnaires. Based on this exercise the following topics will after a short introduction be raised and discussed with the lecturer and members of the EQUAL group

- Generation of items from different sources.
- Interpretation of questionnaire items.
- The influence of the title of a questionnaire on respondents willingness to complete.
- Questionnaire layout & appearance; effects on responding.
- Layout of response option(s) and ease of completion.
- Advantages and disadvantages of different kinds of response options.

5. Introduction to Rasch Analysis; *Alan Tennant/Luis Prieto*

This workshop is an introduction to the basic concepts of measurement, including unidimensionality, item bias, scaling properties, and their link to the traditional psychometrics of reliability, validity and responsiveness. The presentation will explore an introduction to Rasch analysis and its one stop approach to examination of a wide variety of measurement issues. It will also cover a worked example of fitting data from the Nottingham Health Profile (NHP) to the Rasch model. The workshop will also include a discussion of issues arising from the application of IRT. What delegates can expect to learn from the workshop:

- A basic understanding of the principles of measurement.
- A basic understanding of what IRT is trying to achieve.
- What to look for in published papers which use IRT.
- Support links for those who wish to do Rasch analysis.

6. Contribution of cognitive science to the conceptualization and refinement of self-report QOL instruments; *Ivan Barofsky/Jane Lennox*

This session will explore the role of cognitive science in the development and refinement of self-report QOL assessments. The presentation will build on current developments in the cognitive sciences as applied to QOL assessments. It will focus on how cognitive interviews, focus groups, and expert panels can be used to generate relevant, sensitive QOL assessments, and how to use cognitive research methods to evaluate the adequacy of existing instruments or develop new instruments. Participants will have an opportunity to observe and practice cognitive interviewing techniques during the workshop.

Workshop Descriptions Continued...

Afternoon Session (1:30-4:30pm)

7. Introduction to Health State Preference/Utility Assessment; *Dennis Revicki/Sonika Mathur*

This workshop provides an introduction to the theory and methods of health state reference and utility assessment. It includes a basic overview of the rating scale, standard gamble, time trade-off, and multi-attribute techniques. A discussion of critical issues associated with preference/utility measurement, including population effects, contextual effects, cognitive processes, and beliefs and attitudes.

8. Imputation for non-randomly missing QOL data in longitudinal studies; *Diane Fairclough*

This course will examine methods of imputation for missing QOL data in longitudinal studies. Simple imputation methods will be briefly discussed but the focus will be on multiple imputation methods such as Approximate Bayesian Bootstrap (ABB), explicit models, 'closest predictor' and delta-adjustment. We will discuss the strengths and weaknesses of these methods in longitudinal studies with non-ignorable (NMAR) missing data. The workshop will include some hands-on experience with these techniques (participants are encouraged to bring a hand calculator). Participants should have some experience with the analysis of multivariate or longitudinal data.

9. Crosscultural and Translation Issues; *Alain Leplège/Patrick Marquis*

The purpose of this workshop is to examine and discuss the conceptual, methodological and statistical issues that are encountered in projects aiming at measuring perceived health and quality of life in medical setting across cultures. The workshop will be based on the analysis of recent examples.

10. Pediatric QOL Assessment; *Jeanne Landgraf*

Description of Workshop 10 will be posted on the website once it is available.

11. Modern Psychometric Methods, Adaptive Testing, Dynamic Health Assessment, and the Internet; *John E. Ware, Jr./Mark Kosinski/Jakob Bjorner*

This workshop covers advances in methods for monitoring health outcomes based on item response theory and computerized dynamic methods of data collection and processing. The advantages of scoring results, across methods, on a standard metric will be demonstrated for applications, including: (a) population health monitoring; (b) clinical trials; and, (c) screening and monitoring individual patients using computerized dynamic health assessments.

12. Patient Satisfaction Assessment; *Ron D. Hays/Leo Morales*

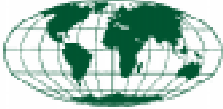
This workshop will introduce basic issues in assessing patient experiences with

health care. Discussion will focus on leading instruments for assessing ambulatory care periodically at the health plan (Consumer Assessment of Health Plans Study Survey) and physician group (Physician Value Check Survey) level. Examples will be provided of instruments for assessing satisfaction with a specific visit and hospital care. Key methodological issues (e.g., reliability assessment, casemix adjustment) in analyzing and reporting results will be presented.

Registration

Register on-line! www.isoqol.org

Registration fees:

	By August 18	After August 18 (but before October 18)	Onsite
			
ISOQOL members:	US\$300	US\$350	US\$400
Non-members:	US\$400	US\$450	US\$500
Student*:	US\$115	US\$140	US\$180

Workshop Fees:

Before August 18: One workshop=US\$100, Two workshops=US\$175
After August 18, 2000: One workshop=US\$125, Two workshops=US\$200

Accompanying Persons**: US\$60

*Please provide a letter from your mentor or a copy of your student identification.

**Includes Welcome Reception on Sunday, October 29 and Conference Dinner on Monday, October 30 at the Vancouver Art Gallery.

For registration, please complete the enclosed form and send it to the ISOQOL Executive Office or **register on-line at www.isoqol.org**. If your registration form with full payment is not received by October 18, 2000 you must register on site.

The Registration Fee includes:

- Participation in the Conference and access to the exhibition area
- Abstracts and program
- Certificate of attendance
- Welcome Reception on Sunday, October 29
- Refreshments/coffee breaks on Monday and Tuesday, October 30 and 31
- Lunch Monday for those that attend the Business Meeting.

Hotel Accommodation

This year's ISOQOL meeting will take place at the Hyatt Regency Vancouver, 655 Burrard Street, Vancouver, B.C., V6C 2R7, Canada, Telephone: (604) 683-1234; Fax: (604) 689-3707.

The Hyatt Regency Vancouver is located in the heart of Vancouver and its business district, adjacent to shopping at Royal Centre and the Sky Train Rapid Transit station. It is also close to all shopping, cultural, and tourist attractions! ISOQOL has negotiated a special sleeping room rate of \$195 Canadian (\$132 US guaranteed) per night plus tax for ISOQOL meeting attendees. Please contact the hotel directly for reservations and mention that you are with the ISOQOL meeting to receive the special rate. Telephone: (604) 683-1234 or toll free into the Hyatt Central reservations office at (800) 233-1234. **The cut-off date for hotel reservations is September 25, 2000;** however, we recommend that you make your reservations as soon as possible to ensure that you will get a room under the ISOQOL block. Any reservations requested after September 25 will be on a "subject availability" basis, at the best rate available. Group rates may apply 3 days prior to and after meeting dates, depending upon availability.

Transportation

The International Airport is serviced by the world's leading airlines so it's easy to reach Vancouver from any major city. And when you land, Hyatt Regency Vancouver is only 20 minutes away in the heart of downtown.

Please make your own flight arrangements. ISOQOL has arranged for you to receive a 5-15% discount off the lowest fare on UNITED, DELTA, and US AIR. Please be sure to give them the appropriate meeting code. If you do not call the airline directly to make your reservations and you have your travel agent make your arrangements, please be sure to give them the meeting codes as well. ISOQOL will get credited for tickets posted.

UNITED: meeting code: 596CD- to make reservations call 1-800-521-4041

DELTA: meeting identifier code: 162098A- to make reservations call 1-800-241-6760

US AIR: meeting gold file number: GF93191467- to make reservations call 1-877-874-7687

Cancellations

All cancellations must be received in writing and all refunds will be paid after the Conference. A \$50 fee will be assessed for cancellations received by August 18. 50% of the total amount will be refunded if cancellation is received by September 25. 25% will be refunded if cancellation is received by October 29. Cancellations received after October 29 will not be eligible for a refund.

Social Events

- An opening reception will be held on Sunday, October 29 at the Hyatt Regency Hotel. This reception is included with the conference registration fee.
- A conference dinner will be held on Monday, October 30 at the Vancouver Art Gallery. The Gallery is located in a historic turn-of-the-century building that was originally constructed as a provincial courthouse. Two of the original courtrooms in the Annex remain, displaying the magnificent oak woodwork and joinery. The Gallery is centrally located and is within walking distance from the Hyatt. The conference dinner is not included in the registration fee; an additional fee is required. Please see registration form.

Accompanying persons are invited to attend these two events--please see registration form for details.

Touring Vancouver

One of the most breathtakingly beautiful cities in the world, Vancouver is truly a spectacular meeting location. Safe, clean, and friendly, the vibrant city promises an endless array of fascinating things to see and do. ISOQOL has organized several tours for accompanying persons. Registration is required prior to October 18.

Saturday, October 28

Grand City Orientation Tour

HIGHLIGHTS: 1,000 Acre Stanley Park, West Coast Nature Indian Totem Poles, Prospect Point and English Bay Beaches, Chinatown and Historic Gastown, Prestigious Shaughnessy residential area, Queen Elizabeth Park with Photo stop at the Sunken Gardens, Panoramic view of the city from Little Mountain, City Centre and Financial District. *Pick-up at 1:00pm at the Hyatt Regency Melville Street entrance, continue on a 3.5 hour tour of Vancouver City tour. Drop-off and dismiss at 4:30pm. Cost US\$30.00*

Sunday, October 29

Victoria Tour

HIGHLIGHTS: Fully escorted tour includes: Priority Ferry Boarding, 90 minute ferry ride through the Gulf Islands, Admission to world renowned Butchart Gardens, University of Victoria, Royal Victoria Yacht Club, Beacon Hill Park, Victoria City Tour, Uplands and Oak Bay scenic residential areas, Scenic Beach Drive, Ample free time to explore world famous Empress Hotel, British Import shops, Parliament Buildings, Provincial Museum, the city centre and the attractions around the Inner Harbor. *Pick-up at 7:15am at the Hyatt Regency Melville Street entrance, continue on a 12 hour Victoria Excursion. Drop-off and dismiss at 7:30pm. Cost US\$80.00*

Monday, October 30

Parks Homes and Gardens Tour with Lunch

HIGHLIGHTS: Admission to Van Dusen Botanical Gardens, noted for its ornamental displays (self guided tour), Queen Elizabeth Park, Sunken Gardens with admission to Bloedel Conservatory, 1,000 acre Stanley Park, English Bay Beach Drive, Lunch reservations at the Fish House Restaurant in Stanley Park, Exotic Chinatown, Historic Gastown, City Centre Shopping District, and the Financial District. *Pick-up at 10:00am at the Hyatt Regency Melville Street entrance, continue on a 6 hour Vancouver Parks and Gardens Tour including lunch. Drop-off and dismiss at 4pm. Cost US\$60.00*

Tuesday, October 31

Mountains & Sea Tour with Grouse Mountain

HIGHLIGHTS: Grouse Mountain Skyride, Capilano Canyon and Suspension Bridge, Nature Trails, Cross Vancouver's harbour on the unique Paddlewheeler. View Vancouver's Trade and Convention Centre from the Harbour, Lion's Gate Bridge, Theatre In The Sky. Tour includes Grouse Mountain Skyride, Paddlewheeler and Capilano Suspension Bridge admission. *Pick-up at 9:00am at the Hyatt Regency Melville Street entrance, continue on a 5 hour Mountains & Sea Tour. Drop-off and dismiss at 2:00pm. Cost is US\$48.00*

Insurance

ISOQOL cannot accept responsibility for personal losses, accidents, or damages to participants and/or accompanying persons. Participants are therefore strongly advised to take out personal insurance to cover any eventuality that may happen during the Conference.

ISOQOL 2000 Scientific Program Committee

Chairs

Diane Fairclough, DrPH, USA
Carol M. Moinpour, PhD, USA
David Osoba, MD, Canada

Committee Members

Neil Aaronson, PhD, *The Netherlands*
Jordi Alonso, MD, PhD, *Spain*
John Brazier, PhD, *UK*
Peter Fayers, PhD, *UK*
David Feeny, PhD, *Canada*
William Lenderking, PhD, *USA*
Donald Patrick, PhD, *USA*
Mirjam Sprangers, PhD, *The Netherlands*

ISOQOL Leadership

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Albert Wu, MD, *USA*

ISOQOL Executive Office

ISOQOL is managed by Degnon Associates
George K. Degnon, CAE-Executive Director
Laura Degnon-Associate Director
Linda Kozlowski-Executive Assistant
6728 Old McLean Village Drive
McLean, Virginia 22101-3906 USA
Phone: 703-556-9222
Fax: 703-556-8729
Email: info@isoqol.org
www.isoqol.org

"Vancouver. Spectacular by Nature."

"Incredible atmosphere..."

*"Sparkling blue waters, snow-capped mountains,
emerald forests, and wide, sandy beaches..."*

"Where wonders never cease."

*"Vancouver welcomes you to
explore its beauty and uncover
its secrets."*



ISOQOL 2000
October 29-31
Vancouver, Canada

"Amazing shops..."

"Boredom not included."

*"From summer's splendour to autumn's golden glory and
sparkling holiday magic--there is always something to see and experience."*

7th Annual Conference of the International Society for Quality of Life Research

October 29-31, 2000
Vancouver, Canada



International Society for Quality of Life Research



Second Announcement and Call For Abstracts
Abstracts Due May 31, 2000
